

Consent Policy Design Group

Guiding Principle Exercise

September 17, 2019

	Accept	Accept with Modifications	Don't Accept
1. Consent policies should require patients be provided clear and unambiguous information about health information sharing choices under Connecticut and Federal statutes. The information should be translated for non-English speakers and should conform to the Web Content Accessibility Guidelines ¹ developed by the Web Accessibility Initiative (WAI), part of the World Wide Web Consortium (W3C). ²			
2. Dependent upon funding availability, consent policies should require Connecticut's Office of Health Strategy to develop an educational resource tool kit on health information sharing, leveraging and adapting content from recognized third-party resources to the extent possible. ³ Educational content should be reviewed and approved by the Health IT Advisory Council, and should not only include information for patients, parents and guardians, but also for providers, pharmacies, labs, health plans, state and local government agencies, and employers.			
3. Information and educational resources on consent policies should be distributed broadly by Health Information Alliance, Inc. (HIA) throughout Connecticut and be made widely available and easily accessible through a variety of sources including the Health Information Alliance, all health and human services agencies and departments in the state of Connecticut, and organizations participating in HIE services in Connecticut.			
4. A review of consent policy considerations should be conducted by HIA, Inc. for each HIE use case			

¹ <https://www.w3.org/WAI/standards-guidelines/wcag/>

² <https://www.w3.org/WAI/>

³ Adapted, with permission, from the CARIN Alliance Trust Framework and Code of Conduct (<https://www.carinalliance.com/our-work/trust-framework-and-code-of-conduct/>)

<p>before an HIE use case is put into production, with a use case-specific consent policy developed if indicated from the review.</p>			
<p>5. Notification of a healthcare organization’s participation in electronic health information exchange should be included in the Notices of Privacy Practices (NPP), as required of healthcare organizations by Health Insurance Portability and Accountability Act (HIPAA). This inclusion in the NPP should be standard practice across the state of Connecticut, whether the exchange of health data is facilitated by:</p> <ul style="list-style-type: none"> a. a national consortium; b. an association of healthcare providers or hospitals on behalf of their members; c. a group of healthcare organizations operating under single tax ID for healthcare payment under an accountable care arrangement; d. a group of healthcare organizations using the same electronic health record system vendor; or e. entities incorporated or designated for the purpose of facilitating electronic exchange of health data. 			
<p>6. Consent policies should result in the lowest possible burden on providers responsible for their implementation and maintenance.</p>			
<p>7. Clearly written information about consent policy changes should be provided by HIA, Inc. to patients, parents and guardians, state and local health and human service agencies, and all licensed healthcare entities in a timely manner when policies or practices have changed, adhering to the principles of broad dissemination and accessibility of information described above.³</p>			
<p>8. Mechanisms, including digital tools, for expressing consent policy preferences should be user-friendly and easily accessible.</p>			
<p>9. Consent policies should explain what will happen to the patient’s data after they withdraw their consent.³</p>			
<p>10. Consent policies should require third-party vendors and contractors be contractually bound by Business Associate Agreements (BAAs) to publish privacy policies of any organization</p>			

facilitating electronic health information exchange in Connecticut, and prohibit use or disclosure of patient information (including de-identified, anonymized or pseudonymized data) for any undisclosed purposes without express consent from the patient. ³			
11. Consent policies should require safeguards be followed consistent with the responsible stewardship associated with protection of a patient’s health information against risks such as loss or unauthorized access, use, alteration, destruction, unauthorized annotation, or disclosure. ³			
12. Consent policies should address sensitive and specially protected data, including, but not limited to, mental health, substance abuse, and HIV status data, in alignment with federal and state statutes.			
13. Consent policies should be aligned with certain national interoperability initiatives, including the Common Agreement (CA) under development as part of Trusted Exchange Framework and Common Agreement (TEFCA), to support the ability to exchange data with entities outside the state.			
14. Consent policies should be reviewed annually (or biannually) to ensure it is aligned with these principles and complies with any changes in best practices or federal or state law.			
15. Consent policies should provide a clear procedure for addressing complaints by individuals regarding the use of their data.			
16. OHS should consider pursuing regulations that define requirements for compliance with consent policies.			
17. Consent policies should require that patients have sufficient time to review educational material before making a consent decision. ⁴			
18. Consent policies should require a consent decision is not used for discriminatory purposes or as condition for receiving medical treatment ⁴ .			
19.			

⁴ Adapted from ONC, HealthIT.gov Meaningful Consent Overview (<https://www.healthit.gov/topic/meaningful-consent-overview>)